



SCI&D SPIRIT

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CATCH the SPIRIT

U.S. Department of Veterans Affairs
VA Boston Healthcare System
Spinal Cord Injuries and Disorders

The Spirit of Success



Ken and Diana Ethier

Ken Ethier is a U.S. Marine Veteran who served his country during the Vietnam era and joined the Massachusetts State Police Department after his military service. Ken worked as a State Police Sergeant until

December 2007, when he broke his neck in a fall at home. He sustained a complete spinal cord injury at C2, resulting in paralysis from the neck downwards and inability to breathe on his own.

After first receiving care in the community, Ken spent six months at VA Boston Healthcare System (VABHS) on the Acute Spinal Cord Injury unit (A-2) in West Roxbury for medical care and rehabilitation. His wife, Diana, was often by his side. It would be a total of nine months before Ken would return to his home.

The Ethiers were determined that Ken would return home after his spinal cord injury. This was always their focus in planning for discharge and continuity of care. In order to transition from hospital to home, Ken & Diana, as a team, learned many things: how to direct home health aides, bowel, bladder, skin and wound management, positioning, transferring, ventilator use, and suctioning. Diana learned how to monitor, identify and manage medical issues in people with complete tetraplegia. She has become an expert in her husband's care and has learned to recognize early signs and symptoms of illness.

Technology has allowed Ken to maintain independence despite his level of injury. He met medical criteria for implanting a phrenic nerve pace maker, which allows a ventilator dependent individual to breathe without the ventilator for periods of time. This gives Ken additional freedom to leave his home, allowing the couple to go out in the yard, to the movies, as well as other activities. Ken can also use a Kindle e-reader, paging back and forth with the use of a mouth stick.

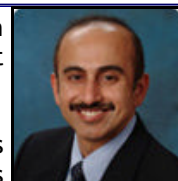
Ken and Diana have taken advantage of several caregiver resources available to them at the VA. The couple uses VA inpatient respite, allowing Diana a well-deserved break from caregiving while Ken continues to receive the level of care he requires. Ken's respite care is provided on A-2 in West Roxbury because that unit is equipped for Veterans with SCI on ventilators. Diana has also been participating in one of the monthly Telephone Caregiver Support Groups since Ken was admitted on A-2. In that group, Diana spoke with the wife of another veteran with SCI who was successfully living at home on a ventilator. This caregiver became Diana's mentor as the couple transitioned home, and the caregivers kept in touch.

Ken and Diana Ethier faced a life changing event in 2007 and have overcome many challenges over the years. They are especially grateful for the many resources available to them through the SCI Center at VABHS and for the physicians and staff, many of whom have worked with them since the onset of Ken's injury. The Ethiers are sure they would not have made it this far without their guidance and support. Ken and Diana's perseverance and courage is one example of the "SCI Spirit" we see in so many of our Veterans with SCI and their caregivers.

Our Response Matters

At an event I attended recently, the keynote speaker was one of the survivors of the Boston Marathon bombing. One quotation from her talk really resonated with me. "It's not what happens to you in life that matters, it's how you react to it."

That statement rang true. I found the message to be uplifting and ultimately, empowering. It makes us aware of our ability to manage and influence our condition regardless of the situation. I see daily examples of it in the resilience of our Veterans and caregivers. The story above is representative of that attitude.



Sunil Sabharwal, MD
Chief SCI/D Services

Our Connecticut Team



The Spinal Cord Injury/Disorders Clinic at VA Connecticut Healthcare System (VACHS) in West Haven, CT serves as a “spoke” site to Connecticut Veterans with spinal cord injuries and disorders. The team includes a board certified spinal cord injury physician (Laura J. Davis, MD), primary care nurse practitioner (Margaret Becker, APRN), clinical nurse (Myrna Padilla, RN), occupational therapist (Paula French, OT), licensed clinical social worker/coordinator (C. Jane Coffee, LCSW), nurse case manager (Susan Gill, RN), and SCI/D health technician (Katie Phillips, HT). The clinic serves over 200 Veterans with SCI/D and provides primary care services to the majority of VACHS Veterans with SCI/D. Care is coordinated with the hub SCI Center at VA Boston as needed.

The VACHS SCI/D clinic has a strong community of peer support. A robust MS/SCI support group meets every Thursday from 11:30 to 12:30 pm in the recreation area. Our Creative Arts Therapist, Marylou Lauricella MA, RDT, has facilitated the group for the past 16 years. The group provides Veterans with a safe haven to access support. Group members discuss caregiver issues, coping with functional limitations, VA benefits, and accessibility needs. Every year we enjoy planning summer barbeques and holiday parties for our Veterans and their families.

Over the past few years, the SCI/D clinic has worked to foster a more seamless partnership with the VACHS Multiple Sclerosis (MS) Clinic. Veterans with MS who require an SCI/D level of care are referred to our clinic immediately after seeing their MS neurologist. Our primary care APRN can then assess the Veteran’s needs, and intensive case management can be provided to those Veterans experiencing psychosocial issues related to their MS symptoms. The SCI/D team meets weekly with the MS Neurology Clinic in order to discuss acute patient needs and referrals.

In 2009, the VACHS SCI/D team created an interdisciplinary ALS Clinic to serve the complex needs of Veterans and families living with ALS. The clinic has grown exponentially since its creation. A comprehensive team of providers meet every Thursday to provide wrap-around services to Veterans and their families. Neurology, Palliative Care, Primary Care, Speech Language Pathology, Nutrition, Occupational and Physical Therapy, Social Work, Nursing, Pulmonary, and Clinical Psychology services all come together to create a comprehensive ALS clinical care plan with the Veteran and his/her family. A strong focus on home-based tele-video services allows the Veteran and family to obtain required services in the comfort of their home.

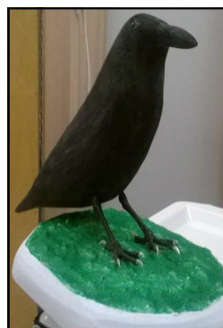
VACHS SCI/D clinic believes in cultivating strong relationships with community supports in order to advocate for every Veteran’s needs. We have valuable partnerships with the Paralyzed Veterans of America, the ALS Association, and the MS Society.

Creative Artists

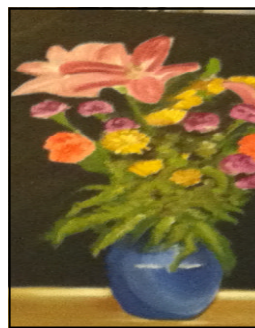
Three Veterans with SCI, Robert Eaton, George Gill, and Jim Smith each submitted an entry into VA’s annual Creative Arts Festival.

The annual local Creative Arts contest has categories that include music, art, drama, dance and creative writing. If an art entry wins on the local level, it is submitted to the national committee for the next level of judging. The National Creative Arts Festival is the culmination of a year-long fine arts talent competition involving thousands of participants nationwide and is open to all Veterans receiving care at VA medical facilities.

The art category is by far the largest category requiring the greatest amount of detail. We wish the best of luck to all three Veterans at the National competition.



Mr. Gill's Entry



Mr. Smith's Entry



Mr. Eaton's Entry



Staff Awards and Activities



Maggi Budd, SCI psychologist (center), & trainees Rachel Lawson and Brianna Strunk presented their research at the 2015 Harvard Psychiatry Research Day at Harvard Medical School on 4/8/15.

Sunil Sabharwal, SCI Chief, was presented the Excellence in Government Award for the 2015 Distinguished Federal Supervisor of the Year by the Greater Boston Federal Executive Board, at a ceremony held at the JFK Museum and Library in Boston.



Donald St. Louis, HT on A2 in West Roxbury is this year's recipient of the Secretary's Award for Excellence in Nursing for the Health Technician category.

SCI Interdisciplinary Conference

The 14th SCI Interdisciplinary Conference was held on Friday, April 10, 2015 at VABHS. Students from several nursing schools heard from the presenters below in this informative program on the fundamentals of spinal cord injury care.



Angela DiTucci, RD
and Kelly Skinner, NP



Jennifer Gannon, RN
& Sherry Clement, RN



Christine Azevedo, RN



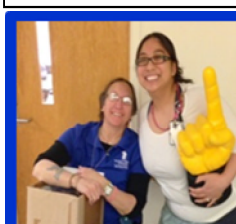
Veteran Wayne Ross and
Jenny McLaughlin, CTRS



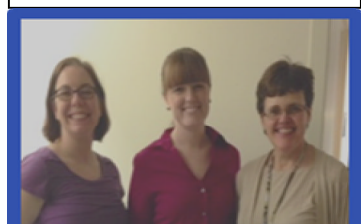
Emma Czazasty, RN
and Erin Carr, RN



Maggi Budd, PhD and
Rachel Lawson, MS



Deb Freed, NEPVA and
Leah Fraielli, RN



Kara Vautour, OTR/L
Bernadette Cummings, OTR/L
and Jeanine Penzo, LICSW

Safety Corner

Staying Hydrated in the Warmer Seasons

Staying well-hydrated is always important, particularly in the summer months when the temperature rises and our perspiration ('sweating') increases. Every day, our bodies lose water naturally through the urine and skin. Taking part in physical activity or spending time in hot weather further increases this water loss, so adequate hydration to replace water in the body is extremely important. Persons with spinal cord injury/disorders may have problems with body temperature control and have a higher incidence of over-heating.

Here are some tips to stay hydrated:

1. Drink *before* you are thirsty. If you drink only if you are thirsty, you have already begun the dehydration process
2. Adjust bladder management (e.g. intermittent catheterization frequency) if needed, based on water intake.
3. Add a slice of fresh fruit such as lemon, lime, or strawberries to flavor up your water

Adapted from: www.NCHPAD.org



VA Boston Healthcare System
1400 VFW Parkway
West Roxbury, MA 02132
800-865-3384
<http://www.boston.va.gov>
Facebook: VA Boston Healthcare System

Veteran Veteran
1 Veteran Way
Boston, MA 02122

Identifying & Addressing Caregiver Burden

Why assess caregiver burden?

To provide the best care to our Veterans, we also need to pay attention to our Veterans' caregivers. Caring for a loved one can be emotionally rewarding; however, some caregiving circumstances can contribute to physical, emotional, social, or financial stress. We see great value in systematically assessing and addressing caregiver burden.

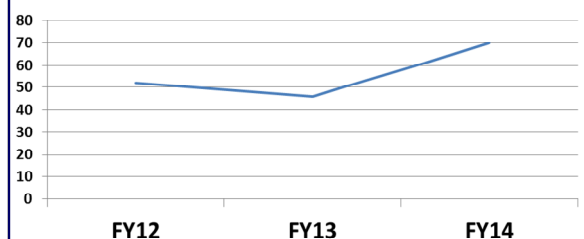
How is caregiver burden assessed?

We administer a brief version of the Zarit Burden Interview (ZBI), a popular self-report measure of perceived burden, to caregivers (See Figure). The ZBI includes a set of statements to which the caregiver is asked to respond, using a 5-point scale ranging from 0 (Never) to 4 (Nearly Always). Specific items from these responses are followed with a more in-depth evaluation of needs and resources when indicated.

What resources are available to support caregivers?

Even simple interventions can significantly improve caregiver burden and its associated symptoms. The VA offers several resources. Respite care available at the SCI Center or in other settings can provide a helpful break while the Veteran is well cared for. Problem-focused education and information, targeted to individual needs, can be very helpful. Additional assistive services or new technology to reduce dependence on caregivers may be indicated in some cases. Support groups can provide valuable camaraderie and help in problem-solving.

Number of caregivers completing the Zarit Burden Interview



Expanding Caregiver Assessment

Our SCI Social Worker administers this interview annually to caregivers who accompany Veterans for their outpatient SCI annual evaluation at VA Boston and to those followed by SCI Home Care since 2012. 70 caregivers were given the interview in Fiscal Year (FY)14 (Figure), and we anticipate these numbers to continue to go up.

We plan to further expand caregiver burden assessment, including possibly completing the interview by phone to reach more caregivers.



CATCH the SPIRIT